

109TH CONGRESS
1ST SESSION

H. R. 1108

To establish the National Center on Liver Disease Research, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 3, 2005

Mr. LYNCH (for himself, Mr. KING of New York, Mr. TOWNS, Mr. McDERMOTT, Mrs. CHRISTENSEN, Mr. MCGOVERN, Mr. ABERCROMBIE, and Mr. CAPUANO) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To establish the National Center on Liver Disease Research, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Liver Research En-
5 hancement Act of 2005”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds as follows:

1 (1) An estimated 25,000,000 people in the
2 United States are affected by a liver or liver-related
3 disease.

4 (2) In excess of \$8,800,000,000 is spent annu-
5 ally to provide medical care for people in the United
6 States with liver disease.

7 (3) There are over 4,000,000 people in the
8 United States who are or have been infected with
9 hepatitis C, 3,000,000 of whom are chronically in-
10 fected.

11 (4) Due to limited research, current treatments
12 for hepatitis C are effective in fewer than 50 percent
13 of the cases.

14 (5) A vaccine has not been developed for hepa-
15 titis C.

16 (6) There are 8,000 to 10,000 deaths each year
17 due to hepatitis C, and the annual death total is
18 projected to increase to 30,000 each year absent in-
19 creased public health and research interventions.

20 (7) Chronic infection with hepatitis B or C is
21 associated with an increased incidence of primary
22 liver cancer, once a rare malignancy in the United
23 States, but now the fastest growing cancer.

24 (8) There are 1,250,000 people in the United
25 States who have been infected with hepatitis B.

1 (9) Up to 15 percent of Asian and Pacific-Is-
2 lander Americans are chronically infected with hepa-
3 titis B.

4 (10) Fifteen out of every 100,000 people in the
5 United States are affected by a chronic, life-threat-
6 ening disease known as primary biliary cirrhosis
7 (PBC), and 95 percent of those affected are women.

8 (11) There is an emerging obesity-related
9 chronic liver disease, nonalcoholic fatty liver disease
10 (NAFLD), which may affect as many as 1 in every
11 4 adults over the age of 18.

12 (12) There are 15,000 children hospitalized in
13 the United States each year due to liver disease.

14 (13) The only option for many individuals with
15 liver disease is a liver transplant.

16 (14) There are over 17,600 people in the
17 United States on the waiting list for a liver trans-
18 plant, but because of the limited supply of livers
19 available for transplantation only approximately
20 5,100 transplants are performed each year.

21 (15) There are 1,400 people in the United
22 States who die each year waiting for a liver trans-
23 plant, and that number is expected to increase.

24 (16) To address the public health threat posed
25 by liver disease, there is a need for the establishment

1 of a National Center on Liver Disease Research to
2 provide dedicated scientific leadership, to create a
3 research action plan, and to ensure the funding of
4 the scientific opportunities identified by the plan.

5 **SEC. 3. NATIONAL CENTER ON LIVER DISEASE RESEARCH.**

6 Subpart 3 of part C of title IV of the Public Health
7 Service Act (42 U.S.C. 285c, et seq.) is amended by add-
8 ing at the end the following:

9 “NATIONAL CENTER ON LIVER DISEASE RESEARCH

10 “SEC. 434B. (a) ESTABLISHMENT.—There is estab-
11 lished the National Center on Liver Disease Research
12 (hereafter in this section referred to as the ‘Center’) in
13 the National Institute of Diabetes and Digestive and Kid-
14 ney Diseases.

15 “(b) DIRECTOR.—The Center shall be headed by a
16 Director, who shall be appointed by the Director of the
17 Institute, in consultation with the Director of NIH, from
18 among individuals with the highest scientific credentials.
19 The Director of the Center shall report directly to the Di-
20 rector of the Institute.

21 “(c) DUTIES.—To ensure the development of in-
22 creased understanding of and better treatments and cures
23 for liver diseases through a dedicated scientific leadership
24 and an adequate allocation of resources, the Director
25 shall—

1 “(1) assist the Liver Disease Research Advisory
2 Board to develop the Liver Disease Research Action
3 Plan; and

4 “(2) encourage and coordinate the implementa-
5 tion of the Plan by the national research institutes,
6 including by issuing research solicitations and by
7 using all other available mechanisms.

8 “(d) LIVER DISEASE RESEARCH ADVISORY
9 BOARD.—

10 “(1) ESTABLISHMENT.—Not later than 90 days
11 after the date of the enactment of the Liver Re-
12 search Enhancement Act of 2005, the Director of
13 NIH shall establish a board to be known as the
14 Liver Disease Research Advisory Board (hereafter in
15 this section referred to as the ‘Advisory Board’).

16 “(2) DUTIES.—The Advisory Board shall advise
17 and assist the Director of the Center concerning
18 matters relating to liver disease research, including
19 by developing and revising the Liver Disease Re-
20 search Action Plan in accordance with subsection
21 (e).

22 “(3) VOTING MEMBERS.—The Advisory Board
23 shall be composed of 18 voting members appointed
24 by the Director of NIH, in consultation with the Di-
25 rector of the Institute, of whom 12 shall be eminent

1 scientists and 6 shall be lay persons. The Director
2 of NIH, in consultation with the Director of the In-
3 stitute, shall select 1 of the members to serve as the
4 Chair of the Advisory Board.

5 “(4) EX OFFICIO MEMBERS.—The Director of
6 NIH shall appoint each director of a national re-
7 search institute that funds liver disease research to
8 serve as a nonvoting, ex officio member of the Advi-
9 sory Board. The Director of NIH shall invite 1 rep-
10 resentative of the Centers for Disease Prevention
11 and Control, 1 representative of the Food and Drug
12 Administration, and 1 representative of the Depart-
13 ment of Veterans Affairs to serve as such a member.
14 Each ex officio member of the Advisory Board may
15 appoint an individual to serve as that member’s rep-
16 resentative on the Advisory Board.

17 “(e) LIVER DISEASE RESEARCH ACTION PLAN.—

18 “(1) DEVELOPMENT.—Not later than 15
19 months after the date of the enactment of the Liver
20 Research Enhancement Act of 2005, the Advisory
21 Board shall develop (with appropriate support from
22 the Director and staff of the Center) a comprehen-
23 sive plan for the conduct and support of liver disease
24 research to be known as the Liver Disease Research
25 Action Plan. The Advisory Board shall submit the

1 Plan to the Director of NIH and the head of each
2 institute or center within the National Institutes of
3 Health that funds liver disease research.

4 “(2) CONTENT.—The Liver Disease Research
5 Action Plan shall identify scientific opportunities
6 and priorities of liver disease research necessary to
7 increase understanding of and to prevent, cure, and
8 develop better treatment protocols for liver diseases.

9 “(3) REVISION.—The Advisory Board shall re-
10 vise every 3 years the Liver Disease Research Action
11 Plan, but shall meet annually to review progress and
12 to amend the Plan as may be appropriate because
13 of new scientific discoveries.

14 “(f) ALLOCATION OF FUNDS.—Subject to the avail-
15 ability of appropriations, the Director of each institute or
16 center within the National Institutes of Health shall allo-
17 cate to liver disease research through peer-reviewed meth-
18 ods, the amounts necessary to fund existing scientific re-
19 search opportunities and, subject to completion and subse-
20 quent updates of the Liver Disease Research Action Plan,
21 amounts adequate to carry out the recommendations of
22 the Plan.”.

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